General

Title

Epilepsy: percentage of all patients with a diagnosis of treatment resistant (intractable) epilepsy who were referred for consultation to a comprehensive epilepsy center for additional management of epilepsy.

Source(s)

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Process

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the percentage of all patients with a diagnosis of treatment resistant (intractable) epilepsy who were referred for consultation to a comprehensive epilepsy center for additional management of epilepsy.

Rationale

Referral to a comprehensive epilepsy center is needed to ensure patients are properly evaluated for epilepsy surgery, have access to ancillary epilepsy resources, and for the use of alternative epilepsy therapies as these treatments are efficacious and may not be provided in general practice (Szaflarski et al., 2008). Epilepsy resective surgery is a potential curative procedure. The superiority of resective epilepsy surgery for control of treatment resistant (intractable) epilepsy over standard medical care has been demonstrated through randomized controlled trials (Wiebe et al., 2001).

Further, alternative treatments for epilepsy, such as neurostimulation, dietary therapy, felbamate and

vigabatrin, are prescribed almost exclusively at epilepsy centers as they have been restricted to patients with treatment resistant (intractable) epilepsy for whom the benefit outweighs the risk for these treatments.

Since a surgical evaluation and other available resources for treatment resistant (intractable) epilepsy can only be performed at a comprehensive epilepsy center, patients with treatment resistant (intractable) epilepsy should be referred for management. These patients will need periodic re-evaluation at a comprehensive epilepsy center to determine whether a new intervention is needed, such as new epilepsy surgery techniques, devices, or an alternative anti-seizure medication.

The following clinical recommendation statements are quoted verbatim from the referenced clinical guidelines or are summaries from the referenced clinical articles and represent the evidence base for the measure:

If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, children, young people and adults should be referred to tertiary services soon for further assessment. Referral should be considered when one or more of the following criteria are present:

- The epilepsy is not controlled with medication within 2 years.
- Management is unsuccessful after two drugs.
- A child, young person or adult experiences, or is at risk of, unacceptable side effects from medication.
- There is a unilateral structural lesion.
- There is psychological and/or psychiatric co-morbidity.
- There is diagnostic doubt as to the nature of the seizures and/or seizure syndrome (National Institute for Health and Clinical Excellence [NICE], 2012).

At the review, children, young people and adults should have access to: written and visual information; counseling services; information about voluntary organizations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services including surgery, where appropriate (NICE, 2012).

Information should be provided to children, young people and adults and families and/or care givers as appropriate about the reasons for considering surgery. The benefits and risks of the surgical procedure under consideration should be fully explained before informed consent is obtained (NICE, 2012).

If the diagnosis or seizure type remains unclear after the initial evaluations, or the patient has recurrent seizures then the patient should be referred to the next level of epilepsy care (Pugh et al., 2007).

If your seizures have not been brought under control after three months of care by a primary care provider (family physician, pediatrician), further neurologic intervention by a neurologist, or an epilepsy center if locally available, is appropriate (Labiner et al., 2010).

If you are seeing a general neurologist, and your seizures have not been brought under control after 12 months, you should insist upon a referral to a specialized epilepsy center with an epileptologist (Labiner et al., 2010).

Among patients with newly intractable disabling mesial temporal lobe epilepsy (MTLE), resective surgery plus antiepileptic drug (AED) treatment resulted in a lower probability of seizures during year 2 of follow-up than continued AED treatment alone (Engel et al., 2012).

Surgical treatment resulted in greater reduction in seizure frequency compared to medical therapy and was a cost-effective treatment option in children with intractable epilepsy (Widjaja et al., 2011).

Despite Class I evidence and subsequent practice guidelines, the utilization of lobectomy has not increased from 1990 to 2008. Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage. Patients who are medically refractory after failing 2 antiepileptic medications should be referred to a comprehensive epilepsy center for surgical evaluation (Englot et al., 2012).

Uncontrolled epilepsy was associated with significantly greater healthcare resource utilization, and higher rates of negative outcomes compared to well-controlled epilepsy (Manjunath et al., 2012).

Opportunity for Improvement

Patients with treatment resistant (intractable) epilepsy are not being referred for epilepsy surgery evaluation; the average duration of epilepsy before surgery in almost all trials is nearly 20 years (Haneef et al., 2010; Engel et al., 2003). A delay in referrals exists despite guidelines and quality measures recommending early referral (Fountain et al., 2011; Wicks & Fountain, 2012; Wasade et al., 2012; Veeravigrom et al., 2013; Erba at al., 2012). Rates of lobectomy have not increased with significant disparities by race and insurance coverage (Englot et al., 2012). This is convincing evidence that patients are not being referred to an epilepsy center for consideration of surgery and other interventions.

The implementation of a quality measure is likely to improve general awareness and encourage specific education for reinforcement to providers and patients about the efficacy of referral to a comprehensive epilepsy center. For example, implementation of an epilepsy quality measure checklist increased surgical referral from 3% to 14% in one clinic (Cisneros-Franco et al., 2013).

Evidence for Rationale

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

Cisneros-Franco JM, DÃaz-Torres MA, RodrÃguez-CastaÃ±eda JB, MartÃnez-Silva A, Gutierrez-Herrera MA, San-Juan D. Impact of the implementation of the AAN epilepsy quality measures on the medical records in a university hospital. BMC Neurol. 2013;13:112. PubMed

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Szaflarski JP, Rackley AY, Lindsell CJ, Szaflarski M, Yates SL. Seizure control in patients with epilepsy: the physician vs. medication factors. BMC Health Serv Res. 2008;8:264. PubMed

Veeravigrom M, French BC, Thomas R, Sivaswamy L. Adherence to quality measures in a pediatric epilepsy center: a pilot study. Pediatr Neurol. 2013 Apr;48(4):291-3. PubMed

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Primary Health Components

Epilepsy; referral; comprehensive epilepsy care center

Denominator Description

All patients with a diagnosis of treatment resistant (intractable) epilepsy (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Patients who were referred for consultation to a comprehensive epilepsy center for additional management of epilepsy (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Importance of Topic

Epilepsy data is lacking. In 2012, the Institute of Medicine released *Epilepsy across the Spectrum: Promoting Health and Understanding*, detailing epilepsy research disparities and highlighting specific areas where further research is needed, including the extent of epilepsy, consequences, comorbid conditions and outcomes of epilepsy (England et al., 2012). The following statistics only touch on the magnitude of epilepsy given lack of research and stigma:

- It is estimated 2.2 million people in the United States are diagnosed with epilepsy, and 150,000 new cases of epilepsy are diagnosed in the United States annually (England et al., 2012).
- Epilepsy prevalence might be underestimated because of underreporting associated with repercussions and stigma in disclosing epilepsy (Kobau et al., 2012).
- Common comorbidities among people with epilepsy include somatic (i.e., fractures, asthma, diabetes, and heart disease), neurological (i.e., stroke, Alzheimer's disease, autism spectrum disorders, chronic pain), and mental health conditions (i.e., mood disorders, attention deficit hyperactivity disorders, anxiety disorders, suicidality) (England et al., 2012; Kobau et al., 2008).
- It is estimated the number of people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP) range from 1 of every 10,000 who are newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery (England et al., 2012).
- People with epilepsy are more likely to be unemployed or unable to work, have low annual household incomes, be obese and physically inactive, and to smoke (England et al., 2012; Kobau et al., 2008).
- People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and negative side effects from seizure medications (Fountain et al., 2011; England et al., 2012; Kobau et al., 2008).
- It is estimated the annual direct medical cost of epilepsy in the United States is $9.6 billion. This estimate does not include community service costs or indirect costs from losses in quality of life and productivity (England et al., 2012).

Opportunities for Improvement

Additional data on opportunities for improvement and gaps in care specific to the epilepsy measures can be located in the updated epilepsy measures.

- A review of 261 patient responses using the PatientsLikeMe survey system indicated a gap remains between recommended care detailed in the 2009 epilepsy measurement set and the care delivered to patients with epilepsy (Wicks & Fountain, 2012).
- The Institute of Medicine noted several gaps in care and opportunities for improvement, including 1) timely referrals and access to treatments, 2) epilepsy care and prevention, 3) education of persons with epilepsy and their families, and 4) the stigma of epilepsy (England et al., 2012).
- Surgery continues to be heavily underutilized as a treatment for epilepsy, with significant disparities by race and insurance coverage (Englot et al., 2012).

Evidence for Additional Information Supporting Need for the Measure

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. 1st ed. Washington (DC): The National Academies Press; 2012.

Englot DJ, Ouyang D, Garcia PA, Barbaro NM, Chang EF. Epilepsy surgery trends in the United States, 1990-2008. Neurology. 2012 Apr 17;78(16):1200-6. PubMed

Fountain NB, Van Ness PC, Swain-Eng R, Tonn S, Bever CT Jr, American Academy of Neurology Epilepsy Measure Development Panel and the American. Quality improvement in neurology: AAN epilepsy quality measures: Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology. Neurology. 2011 Jan 4;76(1):94-9. PubMed

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Kobau R, Zahran H, Thurman DJ, Zack MM, Henry TR, Schachter SC, Price PH, Centers for Disease Control and Prevention (CDC). Epilepsy surveillance among adults--19 States, Behavioral Risk Factor Surveillance System, 2005. Morb Mortal Wkly Rep Surveill Summ. 2008 Aug 8;57(6):1-20. PubMed

Wicks P, Fountain NB. Patient assessment of physician performance of epilepsy quality-of-care measures. Neurol Clin Pract. 2012 Dec;2(4):335-42. PubMed

Extent of Measure Testing

The new epilepsy measures are being made available without any prior testing. The American Academy of Neurology encourages testing of this measurement set for feasibility and reliability by organizations or individuals positioned to do so.

Evidence for Extent of Measure Testing

American Academy of Neurology. Epilepsy update: quality measurement set. St. Paul (MN): American Academy of Neurology (AAN); 2014. 83 p.

State of Use of the Measure

State of Use

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Ambulatory/Office-based Care

Hospital Outpatient

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Individual Clinicians or Public Health Professionals

Statement of Acceptable Minimum Sample Size

Does not apply to this measure

Target Population Age

Unspecified

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Prevention and Treatment of Leading Causes of Mortality

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Clinical Condition

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

All patients with a diagnosis of treatment resistant (intractable) epilepsy*

Note: Refer to the original measure documentation for International Classification of Diseases, Ninth Revision (ICD-9), International Classification of Diseases, Tenth Revision (ICD-10), and Current Procedural Terminology (CPT) Evaluation and Management (E/M) service codes.

**Treatment resistant (intractable) epilepsy* is defined as "failure of adequate trials of two tolerated, appropriately chosen and used antiepileptic drug schedules to achieve sustained seizure freedom."

Exclusions

Unspecified

Exceptions

- Patient is already being seen at a comprehensive epilepsy care center.
- Patient has been evaluated within the past 2 years.
- Patient declined referral.
- Patient has non-disabling seizures. Non-disabling is defined by the treating provider and patient.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Patients who were referred for consultation to a comprehensive epilepsy center* for additional management of epilepsy

**Comprehensive Epilepsy Care Center*: Epilepsy centers that provide comprehensive diagnostic and treatment modalities and access to multidisciplinary teams to address comorbidities that are common in epilepsy. The National Association of Epilepsy Centers has provided details of the essential services, personnel, and facilities at comprehensive epilepsy centers. In general, comprehensive centers will provide diagnostic evaluation including inpatient video electroencephalogram (EEG) monitoring, epilepsy surgery evaluation, access to epilepsy surgery, and staff to address psychiatric and psychosocial issues.

Exclusions
Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Administrative clinical data

Electronic health/medical record

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Unspecified

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Rate/Proportion

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Measure #7: referral to comprehensive epilepsy center.

Measure Collection Name

Epilepsy Quality Measurement Set

Submitter

American Academy of Neurology - Medical Specialty Society

Developer

American Academy of Neurology - Medical Specialty Society

Funding Source(s)

American Academy of Neurology

Composition of the Group that Developed the Measure

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Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

Endorser

American Epilepsy Society - Medical Specialty Society

Child Neurology Society - Medical Specialty Society

Epilepsy Foundation - Medical Specialty Society

Date of Endorsement

American Epilepsy Society: 2013 Jul 29
Child Neurology Society: 2014 Jul 29
Epilepsy Foundation: 2014 Aug 7

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Jan

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

Measure Availability

Source available from the American Academy of Neurology (AAN) Web site .

For more information, contact AAN at 201 Chicago Avenue, Minneapolis, MN 55415; Phone: 800-879-1960;

Fax: 612-454-2746; Web site: www.aan.com .

NQMC Status

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Production

Source(s)

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